

Virginia Bleeding Disorders Program

What is the Virginia Bleeding Disorders Program?

The Virginia Bleeding Disorders Program is a legislatively enacted program established by the Commonwealth of Virginia through the Virginia Department of Health, Office of Family Health Services for the care and treatment of persons with hemophilia and other inherited bleeding disorders. Virginia recognizes that the ongoing medical costs of treating such bleeding disorders often exceed the financial capacity of families, despite the existence of various types of medical and hospital insurance.

The Virginia Bleeding Disorders Program provides a "safety net" for persons with inherited bleeding disorders. The program recognizes the importance of comprehensive hemophilia care and the need for hospitalization and frequent outpatient or home therapy in order to promote the health of persons with hemophilia and related diseases. Therefore, the program seeks to provide coordinated, family-oriented, multidisciplinary services for persons with congenital bleeding disorders.

Who can participate in the Virginia Bleeding Disorders Program?

Any resident of Virginia with Hemophilia A, Hemophilia B or von Willebrand Disease may apply for the program, regardless of income.

What are some of the benefits of the Virginia Bleeding Disorders Program?

The Virginia Bleeding Disorders Program was established out of requests by parents and families to the Virginia General Assembly to assist them in providing quality, affordable care for their relatives with inherited bleeding disorders.

First of all, the Virginia Bleeding Disorders Program acts as a "safety net" for persons with bleeding disorders. Almost 20% of persons with insurance change policies each year. This could be related to divorce, job changes, temporary unemployment or the increased cost of premiums. Also many employers change the coverage of their health care plans with or without employee input. During such transitions, many families have found that comprehensive care and/or factor concentrates were no longer entirely covered. Others have changed policies only to find preexisting condition exclusion for hemophilia care and factor concentrate. Given the expensive nature of hemophilia care, such costs can be overwhelming. Moreover, some families are not aware of their options in maintaining health insurance during such transitions. A major service of the program is insurance case management that assists persons in considering their insurance options and completing the insurance application and enrollment process. The Virginia Bleeding Disorders Program also provides assistance in accessing comprehensive specialty health care services and a medical home, care coordination, information and referral, family-to-family support, training and technical assistance for community providers, transition from child to adult oriented health care system, and promotion of quality assurance and policy development. In addition, the program has a limited amount of money to assist uninsured and underinsured persons to receive care they otherwise could not afford.

Secondly, the Virginia Bleeding Disorders Program supports a system of coordinated, family-oriented, multidisciplinary services for persons of all ages with bleeding disorders. The program coordinator collaborates with the staff of four comprehensive bleeding disorder centers that receive support from federal and state funding to provide comprehensive care in Virginia.

Thirdly, the program coordinator staffs the Virginia Hemophilia Advisory Board. The members of the board are governor-appointed and advise the Virginia Board of Health in issues related to inherited bleeding disorders. The Hemophilia Advisory Board provides a mechanism to address the statewide needs of persons with inherited bleeding disorders

Where are the comprehensive bleeding disorder centers in Virginia?

Pediatric Centers

Bleeding Disorders Center of Hampton Roads
Children's Hospital of The King's Daughters
Division of Hematology/Oncology
601 Children's Lane
Norfolk, VA 23507
757-668-7613
Website: www.chkd.org

Children's National Medical Center
Fairfax Satellite Center, Hematology Clinic
8501 Arlington Boulevard, Second Floor
Fairfax, VA 22031
202-884-3622
Website: www.dcchildrens.org

Pediatric and Adult Centers

Central Virginia Center for Coagulation Disorders
VCU Health Systems
PO Box 980461
1200 E. Broad Street, Room 442
Richmond, VA 23298
804-827-3306
Website: www.vcuhealth.org/cvccd

University of Virginia
Department of Pediatric Hematology
Box 800386
University of Virginia Hospital
Primary Care Center, Room 2202
Charlottesville, VA 22908
434-924-8499

University of Virginia
Department of Adult Hematology
Box 800747
UVA Hospital
Jordan Hall, Room 2352
Charlottesville, VA 22908
434-924-0431

What does the Virginia Bleeding Disorders Program cover?

The Virginia Bleeding Disorders Program covers:

- comprehensive clinic services provided by a team consisting of a hematologist, nurse coordinator, orthopedist, physical therapist, nutritionist, social worker and geneticist.
- hospitalization for severe, emergency bleeding episodes; preauthorized hospitalizations related to the bleeding disorder
- emergency room care for acute bleeding episodes
- required orthopedic surgery (up to age 21 years)
- home infusion training
- physical therapy
- laboratory tests related to the bleeding disorder (including quarterly CD4 or T cell counts)
- factor concentrate and hemophilia-related medications (i.e. Amicar)
- orthopedic appliances such as splints and casts (up to the age of 21)
- imaging procedures (x-rays, CAT scans etc) related to diagnosing or monitoring bleeding episodes

What is not covered by the Virginia Bleeding Disorders Program?

Services not covered include:

- Dental procedures or factor required for dental procedures.
- Elective surgery and/or factor concentrate used in elective surgery or rehabilitation from such surgery.
- Medical care provided out-of-state.
- Unauthorized, non-emergency hospitalizations

- HIV-related medications (Some of these medications may be provided to low-income, uninsured persons through other programs. The nurse coordinator can assist with accessing these programs.)
- Immune tolerance therapy for persons with inhibitors.

Who should I contact for more information about the Virginia Bleeding Disorders Program?

The program coordinator may be reached at (804) 827-3306. The mailing address is:

**Virginia Bleeding Disorders Program
VCU/MCV Station
P.O. Box 980461
Richmond, VA 23298-0461**

Toll free #: 1-866-228-2516